Maryland Cancer Control Plan
Town Hall Meeting
Easton/Salisbury, Maryland
Thursday, August 8, 2002

The seventh Maryland Cancer Control Plan Town Meeting was held at the American Cancer Society's office in Easton, Maryland, with video conferencing to Salisbury, Maryland, on August 8, 2002, from 4:00 to 6:00 p.m. Twenty-eight persons attended the meeting.

Robert Villanueva, MPA, Executive Director of the Maryland State Council on Cancer Control (the Council), opened the meeting. Mr. Villanueva stated that the 22 member Council reviews the needs of the community in relation to cancer and advises the legislature on relevant policy. The Council is providing oversight to the development of a new cancer control plan to be published next year. There are 15 sub-committees and over 300 persons participating in this process. The goal of the Council at this meeting is to gain knowledge of the issues related to cancer control on the Eastern Shore. He asked that participants be frank and open about the topics addressed.

Mr. Villanueva also provided an introduction to the town meeting concept, explaining that it is a way to keep the community involved. He indicated that the comments will go directly to the appropriate committee and will be used as the basis for the cancer control plan. He encouraged the participants to return in the spring for the follow-up meetings and indicated that the list of participants from today's meeting would be kept and used as a mailing list in the future.

He then introduced the panel members: Roger Harrell, MPH, Health Officer Dorchester County and on the Maryland State Council on Cancer Control, Norma Kanarek, PhD, MPH, and Alva Hutchison, American Cancer Society. The panel members will respond to questions and might ask for more information from a speaker.

Participants were asked to follow the Speaker Guidelines (Attachment I) provided to all attendees. Speakers were asked to:

a. Limit remarks to 5 minutes
b. Respond to the 3 questions listed on the Speakers Guide, and/or
c. Relate comments to the 15 formal committee topics (Attachment II)

It was noted that additional comments or concerns could be mailed or e-mailed to Virginia Thomas at UMBC (contact information listed on the Speakers Guide).

There will be Consensus Conference on October 16, 2002, in Baltimore on the recommendations made for the planning process.

Delegate Adelaide Eckardt, District 37B, provided the following written testimony:

1. In your opinion, what are the most important cancer issues in your community?
   Lack of prevention activities
   Cultural response
   Early intervention
   Lack of health care

2. Within your community, what are the primary barriers to accessing cancer prevention, education screening and treatment services?
   Cultural patterns, location of funds for individuals/family intervention

3. What suggestions do you have for programs, partnerships, or services that could be created in your community to address the issues and barriers identified in questions 1 & 2?
   Work through churches and community groups
   Funds for treatment and need for case workers/advocates to help families navigate the system

SPEAKERS

Debbie Goeller, RN, MS.
Health Officer, Worcester County Health Department
Ms. Goeller moderated the session in Salisbury. In addition, she submitted the following testimony, which was presented by:

Marty Pusey
Director of Prevention
Worcester Health Department
Cigarette Restitution Funds Coordinator included
Worcester County has been concerned about addressing cancer issues for many years and, because of that, established a Coalition in 1996. A plan was developed to address the concerns identified as a result of participating in the APEX-PH process in 1997. Over the years, Worcester County has used the Maryland Cancer Control Plans as our models for community planning. There are several areas, which Worcester County would like to bring to the Council's attention. We must begin to see the individual not for specific cancers but looking at that person as a whole. It is critical to deal with the whole person when screening for cancer (e.g., recently, three women were diagnosed with colorectal cancer even though they had been regularly screened for other cancers).
The priorities are:
1. Create a comprehensive cancer risk assessment and screening program.
2. Streamline the statewide cancer screening programs so that we can do multiple screens on one person.
3. Decrease the red tape and reduce the barriers for patients to receive services by creating one form and system for use by all screening programs.
4. Support for the State to pool funds at the State level much like the BCCP has done in order to provide treatment.

5. Consider the use of multiyear (5 year) averages and trends for data as part of the formula in calculating the annual allocations
6. Allow flexibility for planning based on the differences within the jurisdictions. Local plans should be based on local data and local jurisdictions should be able to shift priorities and resources and funds according to the data available.
7. Consider giving additional funding for creative planning especially to smaller jurisdictions.

Becky Wright
Staff Nurse, Dorchester Hospital, Oncology Unit
Need to inform the health care providers regarding the platform of the candidates for governor regarding cancer and cancer funding.
Issues
It is still too easy for young people to access cigarettes.
Not sure if the law is not strong enough to prevent access to cigarettes by youth.
I believe that no cigarettes should be available unless by prescription. No physician would ever prescribe cigarettes and no one would have access.
Rural areas have less access to diagnostic resources (e.g., Mammogram Mobile Van available in the city but not for poor women in a rural area).
Transportation is a huge problem.
Accessing treatment is a problem since there are not enough physicians to serve the persons with medical assistance cards.
Medicaid should also pay for the other things that cancer patients need. For example, patients are exhausted from the treatments but still need to come to hospital for treatment for nausea or other treatment connected problems.
Need to pay for patients to have care at home for secondary cancer problems.

Sally Walling
Wicomico Health Department
Cigarette Restitution Funding Program Manager
Agree with all comments from Worchester County.
There are an insufficient number of specialists on the shore so persons needing a specialist must travel to Baltimore for treatment.
Patient records must be returned when they are treated elsewhere or the local hospital doesn't know the prescribed treatment, side effects, or other problems that may be occurring.
Major hospitals need to send resident and Fellows to hold clinics, do surgery, and teach the local physicians. That way local physicians would know what is really happening.
Reduce the stress of the patients by not having them travel to Baltimore where everything is different, new, and dangerous.

Laura Patrick
Wellness Program
Caroline County Health Department
Barriers
Caroline County is even more rural than the rest of the shore counties.
Workers cannot take time from the job to get screening or care.
Do screenings for all cancers on weekends. Late days do not work because there is still a childcare or work hours problem.

Harry Canter, M.D.
Local Provider
Secure increased funding at a high level for residents and Fellows (who are underpaid) so they will come to the Shore.
Increase fellowship programs to attract more persons into them. .
Support Fellows if they will return to Shore area to practice.
There is not one head or neck surgeon on the Shore.
Allow us to spend the money to bring needed specialists here.

Peggy Ferguson
Talbot County Health Department
Colorectal and Oral Cancer Screenings
Talbot County has expanded the program to include women younger than 40 who need PAP smears and breast exams.
Education is needed to promote prostate and skin cancer screening and treatment.
Funding for breast cancer screening case management is being cut for women aged 40 and over. This means that case managers will be cut.
During the colorectal program we have done 36 screenings and had 3 individuals with polyps. We need to follow up but there are no treatment funds for colorectal cancer.
Need funding for treatment so people do not have to lose everything they have in order to get treatment.
Care and treatment for hospice patients are not available. Many patients have to go across the bridge and cannot be near family and friends.

Alva Hutchison
Do you mean that the screening money on the mid-Shore for colorectal is for diagnosis only? After the screening, is the patient is on his own?

Peggy Ferguson
That is correct. There are no dollars for surgery.
Patients apply for medical assistance if that is denied we have them apply to the hospital for uncompensated care.
Difficult enough to face cancer with insurance but with out insurance it is even worse.

Norma Kanarek
Reading Testimony from
Jake Frego, Executive Director
Eastern Shore Area Health Education Center (Printed copy available.)
Incidence and mortality for oral and pharynx cancers are similar to cervical and melanoma.
Oral cancer continues to receive minimal policy attention or funding.
Most oral cancers are diagnosed at the late stages with fatal outcomes and high payment costs for treatment.
Oral cancers are both preventable and the easiest to detect.
Must reduce the oral cancer mortality rates in Maryland.
Suggestions
1. Increase public education and awareness of the:
    a. Nature of oral cancer
    b. Need for early detection
    c. Benefits from routine dental exams with oral cancer exam components
    d. Need to ask health care professionals to provide an oral exam
    e. Need to use protective lip screens
    f. Need to avoid tobacco use
    g. Need to avoid heavy alcohol use
    h. Avoid the combination of tobacco and heavy alcohol use
    i. Teach the signs and symptoms of oral cancer
2. Increase policy makers, legislators, regulators, and educator's awareness of oral cancer issues.
3. Increase insurance coverage and population access for oral screens.
4. Mandate that Medicaid pay for adult dental exams, including oral exams.
5. Increase awareness if non-dental health-care providers regarding the techniques of an oral cancer screen and appropriate referral procedures. Encourage them to include an oral exam for high-risk patients.
6. Make oral cancer one of the priorities in county cancer planning, DHMH initiatives, legislative actions, and tobacco control activities.

Jane Sandt
Queen Anne's County Health Department
Need after hours screenings for all cancers.
Transportation is always a problem.

Janet Pfeffer
Talbot County Health Department
Want to applaud what the Cancer Council is doing for this planning process.

Robert Villanueva
How much would it help to have a person (Patient Navigator) who would guide providers and patients through the care of cancer patient? For instance, a patient who is diagnosed with breast cancer might not know what to do next, so she calls a Patient Navigator.

Jane Sandt
I already do that as a case management for breast cancer patients in my system. However, for other forms of cancer, there are no case managers and that would be a valuable service.
Need a central person just to assist patients.

Lisa Ashman
American Cancer Society
White Marsh area has a patient navigator pilot program. The program employs Licensed Social Workers with special training in oncology. This is a new program and there are no statistics on how many people have used it.

Alva Hutchison
The Patient Navigator program started as a pilot. It does cover the Eastern Shore. The program was started when we found that calls came in for assistance and we could not meet the needs of the patient on the phone. The patients needed someone in direct contact with them.
Two staff persons are assigned per patient. One works with the patient and the other one gathers information on all the resources available in the community. That way it is easy to connect the patient's need with the resource.
This program works when resources are available. However, if no resources are available, the program cannot create resources. A person always answers 1-800 number.

Norma Kanarek
Would the Patient Navigator work to assist the patients to go to the services in Baltimore? Perhaps to act as a guide to help the patient get through the academic centers?

Audience
Great idea and but patients need a phone to call the navigator.
Many Shore persons do not have phones, or if they have phones, they do not have long distance service or they have no transportation.
Need direct contact in the community so that the person not only works with the patient but also really goes with the patient to the resources if necessary.
Patients need more than a phone number.

Roger Harrell
If the American Cancer Society can give us support, then the locals can come up with the assistance to implement programs. For example, if the Cancer Society covered bad debt, we could do what we do and supplement this with the ACS.
Cancer Control Plan must look at total person and that will not happen with the stovepipe funding we now have.
Train Fellows and bring them here to work.
What can I, as Health Officer, do for the private sector?

Robert Villanueva

The Plan will take19 months to write. We need to know the gaps and barriers and what programs do and do not exist so we can plan to add them.
The Plan runs to 2007. So, we have three years to implement the Plan. The Cancer Council will plug in all the partners we can find to get the best outcome.
We recently had a conference on school diets and vending machines. Teachers were very concerned about both issues. How can we address these issues?

Audience

Develop a good relationship and talk about prevention with schools. The school system is receptive to suggestions but do not always get good advice.
Children get one good meal a day at school. If we look at the culture, we will see that families cut down on food knowing that the child gets those one or two good meals at school. So we do not want to cut out too much food from the children.
Frequently, the kids dump the good food and eat what they want. This is not a simple problem and one meal a day of a good diet will not change the total dietary risk for the child.
Need to deal with the parents regarding the children's diet.
Cancer creates a burden for the patient, the family and the community.
If there is a comprehensive Cancer Control Plan, it will help us look at pockets of cancer and to target all the factors that cause cancer.
All Shore counties are in the top levels of cancer statistics and we need to address those factors.

Roger Harrell

We must change the behavior of the parents regarding the risks of cancer. If we educate the kids, they will turn around and teach the parents.
We must remember that vending machines are funding mechanisms that are important to the schools, so we must find positive ways to make changes.
We need the schools to make the changes. Perhaps we should include the kids when trying to make a difference in their diets.

Robert Villanueva

There are 25,000 cancer cases in Maryland. We know that not all those patients will make it. Are we doing enough for pain control and end-of-life care?

Cheryl L. Short
Maryland Special Populations Cancer Research Network
Nurse with Dr. DeShiels

The health professional sees the families and the patients in the last stages of cancer.
There is a lack of knowledge about the disease and about the end of life.
Here on the Shore, patients do not know how to access resources for screening, treatment, or care.
We must look at how to educate the community regarding these issues. For instance, we held a health fair for all the Shore counties and 200 people came. We screened 75 to 100 persons and sent 2 for follow-up to breast cancer and 3 for follow-up to colorectal cancer.

Need to attract them to the care. A basketball game was held as a way to get men to listen to information about Prostate Cancer. Three hundred people, mostly men, came and listened to the prostate cancer information. So, in some cases the clients are willing but we need to present the information in a format they can accept.
Churches need to be involved since when a person is diagnosed, people turn to the church for assistance.

Roger Harrell
Need to discover the interests of the churches. Ministers will help you if you go to their church or give them huge incentives.
Cannot reach all the people so must do the best you can.
Look at challenges and target them.
End-of-life care is critical. We do have Coastal Hospice but the physician must select patients that are within 6 months of death. Some patients or their families are not accepting of that 6 months time frame being set.
Educate physicians that families may not be accepting of death, and wanting to keep the person at home is also important.
We have revenues to help pay the cost, but Medicaid does not pay for hospice.

Audience
There are many factors for the Shore counties that do not impact the other counties.
Recruit and retain providers, do age appropriate screenings, and educate the public on the levels of insurance that exist.
Non-emergency care for patients is needed, as is the use of telemedicine, training for providers, dental care, and follow-up for all the other aspects of health that are not done by the specialist. Treatment dollars need to go with these.

Wendy Carkin
University of Maryland Statewide Health System
The greatest needs are the financial aspects of care.
We also need to provide educators for the community.
There must be education for the physicians regarding clinical trials so we can draw in clients and physicians.

Atlantic General Hospital
Hospital did collaborate with colorectal screening. The hospital has done many screenings for people with no funds for treatment.
If the planning process is to be effective, the committees must focus on a few major topics. There is only a small amount of money and many things to be done.
Select two or three major issues and put the money toward those for the best outcomes.
Everything needs to happen but if we are not focused and the funding concentrated, we will not make any real changes.
We need to identify who is doing what in the cancer area. Patient Navigator programs would be consistent with the idea of knowing what resources are really there for us to use.
Start so there is no duplication and that we can use models that are successful

Robert Villanueva
When implementation is done, the most money available will be about $1million.
Everyone will look at Cancer Control Plan and the partners pick up the portion of the Plan they can do something about.
This will be a team effort. We can make a difference.
There will be three, five, or seven areas that we identify and wish to address over the years.
Find out what is being done and look at what is needed and match the two.

Terry Willis
Times Community Services MOTA (Minority Outreach and Technical Assistance) vendor for Eastern Shore
In town hall meeting, how many community people attended the other meetings and did you get information from them?
Most committees have agency persons but it is difficult to get people from the community to join and give input.

Robert Villanueva
About 150 people have attended the meetings.
Citizens in coalitions, survivors, and family members have come.
We have tried to recruit some of those people to be on all 15 committees.
But it has been hard for a lot of laypersons.
We hope to draw them to the Oct 16, 2002 meeting to review the recommendations.
Please help us do that.

Terry Willis
Coalitions are a great way to get the community input but we hold them in the evenings.
Maybe we need to change times of committee meetings to evenings so people can come.
Over all we want to include everybody but the process is not inclusive.
Agencies must change the way they do business if they want to get people to participate.

Robert Villanueva
All materials will be on the web prior to the 10/16 meeting and with a 2-3 week to period to testify.
Public comments will be taken after the conference.
If you can get a group, the Council will fund a teleconference so that your community can participate in the meetings.
We have changed our thinking as we have gone through this process. We believe that having 500 people involved will make a big difference in the outcomes and planning.
If you recommend people to us for the meeting or committees, we will help them get there.

Debbie Goeller
Health Officer, Wicomico County Health Department
Thank you for helping us participate in this session.

This has been an excellent step forward.

Melanie Parrish
Upper Chesapeake Health/Healthlink
Pain management / end-of-life care
Recently I had contact with the family of a patient dying with pancreatic cancer. The physician did not refer the patient to us but gave heavy medications. All the patient was doing was sleeping. There was no interaction with the family until they found the pain management specialist. The specialist helped them get the care and pain management that the patient needed. At the end the family had a more positive outcome.
Difficult to know why the patient was not referred for pain management when the physician knows that with pancreatic cancer the outcome is death.
Transportation is an issue in end- of -life care. Poor people in rural areas have no transportation available to get to pain management.
Mammogram mobile vans charges $190 for each one done but it is accessible.
Other freestanding units charge $64 for each one but no transportation to the service.
Many people do not get screened due to fear of the system or the outcome.
Go to the public and educate them.
Get to ministers and you will get to the people.

Jane Pfeffer
Health Educator Talbot
We need to educate people about medications and all aspects of care.
Support all health providers and encourage them to learn about cancer and the needs of the patient.
One cannot impact a community unless you know its attitudes and culture.
Starting Aug 1, 2002, we began a survey looking at where people live and the risk factors that they are exposed to by their life style.
We will use it to see where we can target our programs.
Cancer cannot be segmented, we need to know where to reach people for one cancer risk but we can then be comprehensive and focus on all others that might impact the person.

Bowie Little-Downs
Please participate with the committees. You can use email to respond if you cannot come to the meetings. The minutes are on the web after each meeting. The comments come right back to us. We will see that they are shared with the Council.
We rely on technology to receive your opinions.

Roger Harrell
Community members would say different things at these meetings. People who do not have cancer do not know what to say.
Most of our residents are worried what they will eat tomorrow. They cannot think about another issues even one that will impact their health.
All the groups asked for locals to participate but it is difficult to get them to participate.

Glora Dill
Director of Nursing, Talbot County Health Department
We need education for the providers regarding early referrals for end- of- life care.
If we get the patient at the end- of -life, it is more difficult for us to provide good care.
Providers not have good pain management skills.
Consumers could be hand picked and fed to get them here but you did get wonderful responses from the people present tonight.
Use a forum or focus groups to get the most input.

Melanie Parrish
Upper Chesapeake Health Systems
We go to school system and talk about prevention diets. We also do breast cancer education for high school girls and ask them to share the information with their mother, sisters, and friends. We give shower cards and stickers and get them to start good habits young. The target population was 60 girls, and we had a great response.
There is even a video that targets the teenage girls.
Classes on stress and smoking with education materials are also provided.

Alva Hutchison
Colorectal committee
My committee has a question regarding access to colonoscopy screening through out Maryland.

Audience
The Upper Shore has a wait of up to two months for screening.
It takes 2-3 weeks to get a physician visit and then up to 2 months to get an appointment.
People generally believe that they will not have a good experience with the screening.
The screening site is very busy and there has been an increase due to the publicity.

Worchester County
GI doctor is busy. Takes up to 2 months to get it done. We still continue to use the colonoscopy and, if we can recruit a new doctor, we will improve the service.

Maria Matos
TLC
Work with Asian, farm, and Hispanic populations.
They do not know where to go or what to do and need help.

Bill Molloy and John Hannigan
Man to Man of Delmarva
Submitted as written testimony
Man to Man Prostate Cancer Support, is sponsored by the American Cancer Society.
There are multiple partners with agencies, community businesses, and church groups.
The group attends Health Fairs, has monthly meetings, and speaks to their organizations on the subject of Prostate Cancer. The group has recently presented in the state prison in Princess Ann at the request of the American Cancer Society.

1. A lack of funding and a lack of public awareness about cancer.
   Some medical personnel are not up to date on current procedures or are slow to accept new procedures.
2. The poor and uneducated have a hard time accessing prevention programs.
   They lack the education to know where to get services, such as screening, and treatment
   Once again lack of funding is an issue.
3. Man to Man is working in these areas to educate and establish partnerships to address the problems listed in Question 1 and 2.

Robert Villanueva

He thanked the participants.
Will be back in the spring with the plan for review.

Roger Harrell

He thanked Robert and his staff for the vision

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